GENE NEWS

A Publication of the Hawai`i Department of Health Genetics Program

Volume 6 Issue 4
December 2007

Why is My Family History Important?

"Many of us have heard or used the phrase, 'it runs in the family,' but how many of us have stopped to think about what this really means?"

Many of us have heard or used the phrase, "it runs in the family," but how many of us have stopped to think about what this really means? As more genetic discoveries occur, the link between common health conditions and family history is becoming more defined. In the past we may have realized that diseases such as cancer, heart disease, and diabetes seem to run in families, but with today's advances in genetic research we are learning more about why this is the case. For this reason, family history is becoming a very important tool in primary health care and has often been called the "first genetic test."

Despite its importance, most families do not discuss their medical histories. Additionally, physicians and nurses may only have enough time in a visit to obtain a brief family history. However, there are many important reasons to know your full family history:

- **Awareness and prevention**. With increased awareness of a disease that runs in the family, an individual can make their physicians aware of their family history and steps can be taken early to prevent and/or monitor for signs of the disease.
- **Determine your risks**. Red flags in a family history could lead to the availability of genetic testing to provide a better risk estimate for the disease.
- **Comprehensive risk information**. Sometimes a complete family history can link together different diseases within a family that may have previously seemed unrelated and not inherited.

This issue of GeneNews will provide you with the examples of how family history is important as well as some simple tools and resources to begin collecting your own family history. **An important key to prevention is awareness and your family history can become one of the simplest yet most powerful tools available to you and your family.** Begin constructing your family history today!

Coordinator's Corner

The Hawai'i Genetics Program wishes you a very Happy and Healthy Holiday Season!

The holidays are usually a time that families spend together reconnecting. This year, your family can do one of the most important activities to help keep your family healthy – collect a good medical family history. We have provided information and resources in this issue of GeneNews to help you collect your family history to share with your health care providers.

On a very happy note, a big congratulations go out to Elaine Marr, Sarah Scollon, and Arthur Yu for passing their American Board of Genetic Counseling examinations! This means that all the Hawai'i counselors that took the board examination this summer were successful. This brings the total number of board certified genetic counselors in Hawai'i to twelve.

INSIDE THIS ISSUE

Linda Lingle
Governor of Hawai'i

Chiyome Leinaala Fukino, M.D.
Director of Health

Hawai'i Department of Health
Children with Special Health Needs Branch

(808) 733-9055
(808) 733-9068(fax)
www.hawaiigenetics.org

For questions or comments, please contact Sylvia Au at sylvia@hawaiigenetics.org

family

FAMILY HISTORY CASE SCENARIO

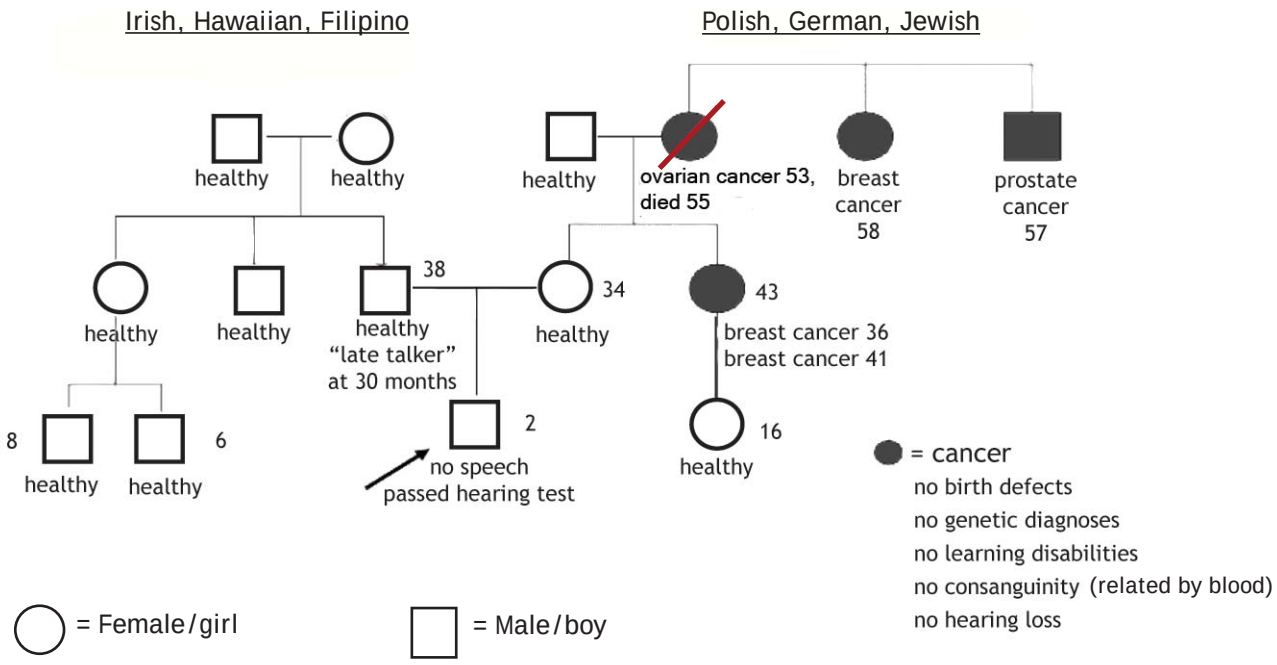
"Mutations in two genes, BRCA1 and BRCA2, have been found to cause a predisposition to cancer, particularly breast and ovarian cancers."

Simon was referred to Genetics Clinic due to speech delay. At age 2, he had not yet spoken any single words, but his gross motor and fine motor skills were well-developed. He walked, used a spoon to eat, and grasped a crayon to draw. The genetic counselor asked questions about the family history and developed a three-generation pedigree.

No maternal (mother's) or paternal (father's) relatives were born with birth defects, had learning disabilities, or were diagnosed with a genetic disorder. Simon's cousins were healthy and reaching appropriate developmental milestones. Some children with speech delay may have hearing loss, but Simon passed a recent hearing test. Simon's father said he was also a "late-talker" – he didn't speak until age 2 1/2 years.

Simon received speech therapy through Early Intervention Services and had learned some sign language. The doctor recommended that Simon continue speech therapy and return for a follow-up genetics appointment in 6 months. If he had not started to speak at that point, some basic genetic testing would be considered. Simon's parents were happy with this plan.

The family came to Genetics because of Simon's speech delay, but the genetic counselor noticed another possible concern when drawing the pedigree. When she asked if any relatives had a history of cancer, there were none on the paternal side.



However, several maternal relatives had different types of cancer. Simon's maternal aunt was diagnosed with breast cancer at age 36 and again at age 41. His maternal grandmother had ovarian cancer at age 53 and passed away at age 55. His maternal great aunt had breast cancer at age 58, and his maternal great uncle had prostate cancer at age 57.

The genetic counselor explained that the pattern of cancers in the family could indicate an inherited cancer predisposition syndrome. Mutations in two genes, BRCA1 and BRCA2, can cause a predisposition to cancer, particularly breast and ovarian cancers. People in particular ethnic groups, such as Ashkenazi Jews, have a higher risk for mutations in BRCA1 and BRCA2. Mutations in these genes are more likely if the family has relatives:

- diagnosed with cancer at younger-than-expected ages (Simon's maternal aunt)
- with more than one primary diagnosis of cancer (Simon's maternal aunt)
- with ovarian cancer at any age (Simon's maternal grandmother)

Simon's mother had not heard of these genes, but wanted to pursue more aggressive cancer screening. She increased her clinical breast examinations from once to twice a year and scheduled a mammogram. She decided to discuss the option of genetic testing of the BRCA1 and BRCA2 genes with her family.

In this case, the pedigree identified potential inherited risk factors beyond the original referral. One year later, Simon has responded well to speech therapy. He speaks in sentences and enjoys preschool. No medical cause for his speech delay was identified. Simon's mother attended another genetics appointment with her sister, niece, and aunt. The sister chose to have BRCA1 and BRCA2 genetic testing; results are pending. Meanwhile, Simon's mother had a normal mammogram and is performing regular self-breast examinations, and her niece has started regular screening.

The following is a list of tools and resources you can use to create your own family health history. Once you have completed your family history, bring it to your next doctor's appointment.

Tools & Resources for Families:

My Family Health Portrait
(www.familyhistory.hhs.gov)

This online tool was developed by the U.S. Surgeon General. By asking specific health questions about your family, the tool helps you create a personalized family history report and family tree. Although it focuses on certain diseases, you can add other conditions that are common to your family.

Family Health History Questionnaire
Developed by March of Dimes
(www.marchofdimes.com/files/GYP_PrenatalQuestionnaire.pdf)

For use by couples expecting a child or thinking of having a child, this questionnaire can be filled out and brought to your obstetrician.

Family Health History Toolkit
(www.health.utah.gov/genomics/familyhistory/documents/Toolkit/new%20entire%20toolkit.pdf)

The Utah Department of Health developed this toolkit to help you talk to your family about family history. It includes 10 questions you should ask your family, fun ideas to get your family talking about family history, when to see a genetic counselor, and genealogy resources.

Genetics Education Resource
(www.genednet.org/pages/consumer_family.shtml)

This webpage explains how to collect a family history and what to do after you have completed it.

history

Hawai'i Department of Health
Genetics Program
741 Sunset Avenue
Honolulu, HI 96816

Family History Resources for Health Professionals

Resource Packet for Health Professionals
(www.hhs.gov/familyhistory/respachealth.html)
Created by the U.S. Surgeon General, this packet was compiled to help health care professionals educate the public about the importance of family history. It consists of case studies, posters, online resources, and a powerpoint presentation entitled "Family History is Important for your Health."

American Medical Association
(www.ama-assn.org/ama/pub/category/2380.html)
Developed for health care providers, this site contains information about the importance of family history, a prenatal screening questionnaire that can be used for patients, a pediatric questionnaire, and an adult family history form.

Family History Public Services Announcement
(www.genome.gov/Health/)
These five public services announcements were developed by the National Human Genome Research Institute in cooperation with the Office of the U.S. Surgeon General for health care providers. Featuring stories about how increased healthcare provider family history knowledge can improve the health of all Americans, these announcements are available for download.

Center for Disease Control
(www.cdc.gov/genomics/famhistory/famhist_yoon.htm)
Can Family History Be Used as a Tool for Public Health and Preventative Medicine?
This article, published in 2002 in Genetics in Medicine, provides arguments for using family history to stratify risk for common chronic diseases.